

Addressing Invisible Injuries: Child Neglect, Exploitation, and Emotional Abuse Conference

April 2, 2009

10:30am-12:00pm

Workshop: "Working effectively with Parent with Cognitive Challenges"

Resources attached

Stress-o-Meter Exercise

- 1. First assess your stress in the different life domain areas. Add life domain areas if needed.**
- 2. Identify the specific situations that cause you stress in those life domain areas**
- 3. Prioritize the most stressful and highest risk**
- 4. Brainstorm proactive and reactive strategies**
- 5. Pick the strategies you are most likely to implement**
- 6. Write up your plan with who is responsible and by when**
- 7. Implement the plan and revise at least monthly**

STRESS-“O”-METER



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Spiritual/ Cultural		Safety		Legal		Health/ Medical		Finances		School	

Guiding Principles

Supporting Families Headed by Parents with Cognitive Limitations

By Howard Mandeville

The issues of families headed by parents with cognitive limitations are notable for their ambiguity. They do not present the open and shut, black and white circumstances that lend themselves to clear-cut laws, policies and agency procedures. Much is left to the judgment of the person the family turns to for support.

To assist support agencies in sorting out the ethical dilemmas encountered in helping parents who have cognitive disabilities and their children, the Supported Parenting Project offers the following guiding principles.

All people have fundamental rights, regardless of disability. The rights of any citizen to pursue life, liberty, and happiness are not conditional on a citizen's disability or need for support. The right to take on family roles and live in the community cannot be abrogated merely because a person has a disability.

Parents must be partners in support services. Parents, regardless of the characteristics that challenge their ability to parent, have a special bond of kinship and commitment with their children. They are best served when they are encouraged and supported to be a part of the service planning and decision-making process, and empowered to be partners in the services developed for their children. When support is organized from a family-centered perspective—"what can we do to support the survival of this family?"—interventions are more likely to be mutually agreed upon and involvement with outside support is seen as less threatening by the family.

Build on family strengths. Children's greatest resource is their family. Often, an agency's involvement with a family is on the child's behalf and intervention is framed solely by parent deficits. The parent is seen as a problem, not as a "developing resource" so the worker develops a skeptical and punitive posture. The parent's perceived

shortcomings become such a prominent focus that contributing factors such as poverty, powerlessness, lack of community resources, and the stigma associated with disability recede from conscious attention. Seeing the family only in terms of its deficits diminishes both the family and the support system's ability to be helpful. Parents known for their disabilities also have some abilities—they have skills that our support services can help them enhance. Family bonds cannot be replaced painlessly by any array of services or alternate care arrangements. The way to support parents is to strengthen their capacities and internal resources.

Do no harm. The weight of a support system on a family seen as needing help can be burdensome. There is a tendency of the service system to take control and erode personal autonomy. The social costs of the harm caused by well-intentioned interventions may outweigh both the benefits of intervention and the risks of not intervening. This is not to say that there is no role for formal support services. It only means that we need to be careful to insure that the "act of helping" does not overwhelm a family and/or transform it beyond recognition. Agents of the service system need to resist the temptation of taking control away from parents.

Support community and family membership. Parents with impaired functional skills and their families have always been in our communities but not always recognized as such. Often, families did not emerge to be noticed by the formal support system because they were absorbed and assisted by their extended family members. Our services should not displace the roles of extended family members, friends, neighbors, or other community resources. Families are best supported in

the context of their extended families and their communities. Successful support services value the integrity of the family and help to provide links to traditional family and community resources. When families seem to be cut off from extended family and community, what can be done to bring them back into roles that mutually acceptable? When friends or extended families seem to be contributing to the instability of the family, how can their interest in the family be saved while their seemingly harmful input redirected? Given an individual family's interests and preferences, what are the community resources

Parents known for their disabilities also have some abilities—they have skills that our support services can help them enhance.

Children's Services

PRACTICE NOTES

For North Carolina's Child Welfare Social Workers

From the N.C. Division of Social Services and the Family and Children's Resource Program

Vol. 9, No. 2
January 2004

Family-Centered Practice with Parents with Cognitive Limitations

In family-centered child welfare practice the family is the primary unit of attention. Respecting, strengthening, and supporting the family – while guaranteeing child safety – are the hallmarks of this method.

Using this approach with any parent requires resourcefulness and conscious effort. To identify and build on a parent's strengths, child welfare workers must first believe that the parent has strengths to build on. This can be difficult when, as so often happens, there are significant cultural and socioeconomic differences between the worker and the parent. When the parent in question has cognitive limitations, workers may find the family-centered approach doubly challenging.

Attitude Matters

Believing in the potential of the parents you work with is critically important to family-centered practice. Research indicates this is especially true when parents have cognitive limitations. One study found that families whose children were removed permanently typically had only limited support, lost their support at a crucial time, or were viewed as incompetent by key figures within their support system (Espe-Sherwindt & Kerlin, 1990). Another found that the ability of parents with learning difficulties to succeed is significantly influenced by the attitude of the helping professionals, family members, and others who make up the family's support network (Tymchuk, 1990).

This suggests that child welfare workers' values and attitudes towards parents with learning difficulties are just as important as their knowledge and skills (Booth & Booth, 1993).

Overcoming Biases

Yet believing in parents with cognitive limitations can be difficult, especially for those struggling with personal stereotypes and prejudices about people with developmental disabilities. The following discussion of research findings may make it easier to overcome

these biases:

People with cognitive limitations can be good parents. Research has found that the ability of a parent to provide adequate child care is not predictable on the basis of intelligence alone (Booth & Booth, 1993; Field & Sanchez, 1999). When they succeed as parents, people with intellectual disabilities often do so on the strength of their emotional interactions with their children and—especially—on the strength of their social supports.

This is not to say that every adult with developmental delays is or can be a good parent. Like everyone else, the ability of people with learning difficulties to parent successfully depends on a wide range of factors, including environmental stresses (unemployment, housing issues, other crises), the models of parenting to which they have been exposed, and the strength of their support network.

Studies have shown that people with intellectual limitations often exhibit similar parenting deficits, such as failure to adjust parenting styles to changes in their child's development, a lack of verbal interaction with the child (especially failure to praise), and insufficient cognitive stimulation. Critics of these studies point to their methodological flaws, most notably their failure to control for the effects of poverty (Booth & Booth, 1993).

Children can do well in these families. Many children raised by parents with cognitive limitations go on to lead healthy, normal lives, despite the fact that the environments in which they are raised are filled with difficulties (Booth & Booth, 1998a). Protective factors that make it possible for these children to succeed include personal traits (sociable, responsive to others, outgoing), family characteristics (warm, stable, and secure), and external factors such as supportive relationships outside the home and participation and involvement in the wider community (Booth & Booth, 1998b).

At the same time, research has found that children of parents with cognitive limitations are at risk for a number of negative outcomes, including developmental delay, poor school performance, and removal from their families. Though they may be due more to poverty than parental disabilities, these risks are recognized by our service delivery system. For example, having a parent with cognitive limitations is one of the risk factors that can make a young child eligible for early intervention services in North Carolina.

Parents with cognitive limitations who need improvement can often learn to be better parents. Even when people with cognitive limitations have clear deficits in their parenting skills, research suggests appropriate training can help them improve (Thompson, 1984; Feldman et al., 1989; Whitman et al., 1989). Specially designed training courses have been shown effective in teaching parents to nurture their children, to express their affection appropriately, and to learn essential parenting skills such as menu planning, grocery shopping, and techniques for managing problem child behaviors (Field & Sanchez, 1999).

Reflecting on this research, the bottom line is that people with cognitive limitations are like other people—some will be good parents, some will not. The only way to assess and support

them is on an individual, person-by-person basis.

Finding Strengths

Many parents with cognitive limitations are isolated, poor, and unused to thinking of themselves and their lives in strengths-based terms. To discover family strengths social workers need to use observation and creativity.

For example, a child welfare worker could react with dismay at the sight of a mother and her children eating off a newspaper "table" on the floor. Alternatively, he could see it as a demonstration of the mother's ability to establish a mealtime routine and to solve the problem of having no furniture. If he can see and build on small successes in a difficult situation, the social worker has the opportunity to build the parent's self-esteem, dignity, and competence (Espe-Sherwindt & Kerlin, 1990).

In seeking to support parents with cognitive limitations, child welfare workers should actively seek out and/or try to develop benefactors for them. A **benefactor** is someone without learning difficulties who helps with the practical difficulties of coping with everyday problems (Edgerton, 1967). "The one feature that has consistently been shown to distinguish families where the children remained at home from families where the children were removed is the presence of another adult able to give extended daily support" (Booth & Booth, 1993).

The presence of a benefactor can be essential to the success of one of the most important family-centered strategies practiced in North Carolina – child and family team meetings.

Child and Family Team Meetings

Research and the direct experience of child welfare workers indicates that parents with cognitive limitations sometimes resist efforts to support them. "One study found that their opinions strongly diverged from the views of social workers 85% of the time" (Field & Sanchez, 1999). Child and family team meetings may be one of the best strategies for overcoming this barrier, since they allow parents to help create their own service plans.

Joan Pennell, of NC State University's Family-Centered Meetings Project, has these suggestions for involving parents with cognitive limitations in child and family team meetings:

1. Take time to explain and re-explain the process to the parents. Expect the preparations to be longer.
2. Involve "benefactors"/support people (e.g., family's pastor, trusted relative) who can help the parents understand what is happening and make sure their views are heard at the conference.
3. Include in the plan someone from the parents' support network to help them follow through on the action steps and get help as needed.

Janice Doyle, a family assessment worker from Alamance County DSS, has held child and family team meetings with parents with cognitive limitations. She urges caution when inviting people to meetings. Because parents with developmental disabilities typically have so many issues and can be involved with so many systems, she says, child welfare workers may be tempted to invite lots of people. "Sometimes," she says, "that can be a mistake."

Like other people, these parents can feel threatened when surrounded by professionals and strangers in child and family team meetings. Doyle says that one mother she worked with felt so overwhelmed that she shut down. "She stared at the ceiling without responding," Doyle says. "People didn't know what to think. But when I talk to her one-on-one and let her be the expert I find she's a totally different person."

We hope the points below, taken from the articles in this issue, will prove useful to you in your efforts to provide family-centered services to parents with cognitive limitations.

References for this and other articles in this issue

Key Points

- **People with cognitive limitations are like other people** – some will be good parents, some won't. Social workers should assess parents with cognitive limitations as individuals, hold them to the same standards as other parents, and provide them with educational and supportive services appropriate to their needs.
- **Individuals with cognitive limitations have a right to have and to raise children.** Do not presume a parent is incompetent simply because she is cognitively limited. Approach each family with an open mind.
- **Most parents with cognitive limitations are poor.** Neglect may be the result of poverty or other factors, not the parent's mental capacity.
- **Provided the right supports and appropriate education, people with cognitive limitations who are struggling as parents can often provide effective care for their children.** Agencies have a responsibility to provide the services these families need to stay together.

Tips on Facilitating Wraparound with Individuals with Cognitive Difficulties:

- Use visual aids whenever possible
- If you use the story board you may want to use pictures instead of words
- Try to find out what their learning difficulties may be and adjust your facilitation style based on that. For Example, if they have some auditory processing problems, it is very important that you tie everything together visually. If there is visual processing problems, they may want to tape the meetings with everyone's permission
- Have them do with someone rather than provide written instructions or give directions, i.e. Have someone be there when they make phone calls, fill out job applications with them, etc. There is a balance from helping them through it and doing it for them.
- Be as concrete and specific as possible
- Learn their strengths in how they accomplish tasks and model that whenever possible
- Utilize other discipline like occupational therapist, music therapist or speech therapist to name a few
- Repetition is important so provide lots of opportunities to practice skills that are more real life versus classroom
- Don't underestimate their abilities based on learning disabilities or IQ. This should NEVER be a predictor of someone's ability. You should consider what they want and are motivated to do and then develop the steps to get there. The process of working toward a goal is just as important as the product.
- It is very important to individualize interventions for each family member based on needs and not the services. It is very important to be creative and not rely on traditional services or interventions. I.e. Parenting classes may not be extremely useful but parenting modeling using repetitions with someone else may be.
- Utilize the planning clock method that is outlined in your manual. This allows you to see what is happening throughout the day (24 hours, 7 days a week), and then provide the necessary support.
- Crisis and Safety plans should be very specific with only a few steps. Keep it simple.
- Only work on one thing at a time
- Use simple language and be very direct but not confrontational

GUIDELINES

for working effectively with families of children with disabilities

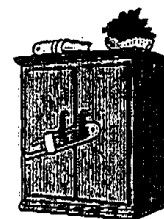
1. Understand how your **VALUES** and **ATTITUDES** affect the way you interact and work with families. Work to understand other's values but don't set out to change everybody.
2. Develop your own **COMMUNICATION SKILLS** so that you are skillful and effective at listening, interviewing, conveying sensitive information, and working with parent/s as team members and partners.
3. Demonstrate utmost **RESPECT** to the children and families with whom you work. "Respect begets respect."
4. **EMPOWER** the families with whom you work by providing them with information and helping them develop skills so they can act on their own behalf.
5. Be proactive. Help families see existing **STRENGTHS** and actions that can be taken. Avoid the deficit model mentality.
6. Remember that all families with children who have disabilities are not homogeneous, rather a heterogeneous group with individual strengths and needs. Remember to **INDIVIDUALIZE** not generalize.
7. When parent/s are willing to express how they feel, provide support by **VALIDATING** their feelings, but do not indicate that you know how they feel unless you have actually been there. Have you "...walked in their shoes?"
8. Be **NONJUDGEMENTAL** in your actions when working with families. Most things in life can be done in more than one acceptable and effective way. It may be different than your way, but is it wrong?
9. Be **SENSITIVE** to the needs of all individuals within the family system. Be knowledgeable and prepared to provide resources and make referrals.
10. Understand the cyclical nature of grieving so you are able to appropriately **SUPPORT** the families with whom you work.
11. When working with families from a **RACE** or **CULTURE** different from your own, educate yourself so you understand their beliefs including their view of having a child with disabilities.
12. Utilize a family-centered approach. Recognize parent/s as the **DECISION MAKERS**. You provide information, parents make the decisions.
13. Understand the unique needs of each family which will enable you to have **APPROPRIATE EXPECTATIONS** regarding the children and families with whom you are working.
14. Help families identify and utilize **EXISTING SUPPORT SYSTEMS** and help develop new ones as needed.
15. Support children with disabilities and their families by **ADVOCATING** on their behalf.
16. Be supportive to families as this helps them to be **RESILIENT**. Resilience is the ability to bounce back from stress.

This list is **NOT** presented in order of priority, rather all guidelines are **IMPORTANT** when working with families and should be happening **SIMULTANEOUSLY**.





Home Safety Checklist for Families with Young Children



Yard

- ☐ Inspect yard regularly for glass, metal, sharp objects, etc.
- ☐ Place poisonous plants out of reach of children
- ☐ Keep children away from any drowning hazards outdoors: Standing water, fountains, etc.

Kitchen

- ☐ Lock up all sharp objects and toxic products
- ☐ Store small appliances out of reach
- ☐ Store large or heavy objects in the bottom cupboards
- ☐ Place glass or breakable objects out of reach
- ☐ Remove stove oven knobs or purchase safety knobs
- ☐ Do not use tablecloths in the kitchen
- ☐ Store plastic sheeting materials or bags out of reach
- ☐ Knot plastic bags
- ☐ Cook on rear burners on stove when possible
- ☐ Turn pot and pan handles toward the back of the stove

Bathroom

- ☐ Lock up all sharp objects, drugs, cleaning and hygiene products
- ☐ Install slip resistant adhesives in the bathtub
- ☐ Buy bathroom products in plastic containers, avoid buying glass containers
- ☐ Do not use water tank toilet disinfectant
- ☐ When bathing your child, check water temperature with your elbow-water should be lukewarm and room should be warm
- ☐ Ensure that a locked bathroom door can be opened from the outside
- ☐ Turn hot water heater down to 49°C or 120°F
- ☐ Never leave a child unattended in or near water

Living Room

- ☐ Pad sharp edges on furniture
- ☐ Fasten bookshelves or tall furniture to the wall with brackets
- ☐ Install locking devices or plastic covers over electrical outlets
- ☐ Remove heavy or breakable objects from tables
- ☐ Restrict access to areas behind electrical units (stereo, TV, etc.)
- ☐ Secure window blind cords
- ☐ Ensure that all plants are non-toxic
- ☐ Keep fireplace hearth guards in place

Bedrooms

- ☐ Place crib away from doors and windows
- ☐ Secure window blind cords
- ☐ Ensure nursery furniture is solidly constructed and has round edges
- ☐ Ensure that crib meets manufacturing standards (no more than 2 3/8" space between rungs and mattress support must be firmly secured)
- ☐ Remove heavy blankets
- ☐ Place diaper pail and changing supplies out of reach
- ☐ Buy only non flammable sleepwear

Stairs

- ☐ Keep stairways well lit
- ☐ Remove all items at the bottom and on the stairs (shoes, toys, etc.)
- ☐ Install handrail at child height
- ☐ Install thick rug at bottom of stairs and thick underpad
- ☐ Install gates at both the bottom and top of stairs

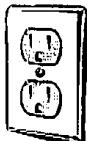
Basement/Garage

- ☐ Lock doors to garage, workshop, laundry room
- ☐ Lock up all toxic chemicals, gardening tools and supplies
- ☐ Store power tools with blades and bits removed
- ☐ Lock firearms and ammunition in a secured cabinet
- ☐ Ensure that large containers which automatically lock from outside have additional locking devices

Other

- ☐ Have a first-aid kit that is easily accessible and stocked with emergency items
- ☐ Never leave candles unattended or accessible to children
- ☐ Practice safety around animals; don't leave children unattended around pets or other animals, do not approach or pet stray animals
- ☐ Install UL-listed smoke alarms on every level of your home
- ☐ Test smoke alarms once a month and replace batteries every year
- ☐ Install a UL-listed carbon monoxide detector near bedrooms in home
- ☐ Check the U.S. Consumer Product Safety Commission website at www.cpsc.gov to find out if your crib, toys or other items have been recalled

Information adapted from "Child Safety Checklist" www.homesafetycouncil.org and "Home Safety Checklist" www.safekid.org/home.htm



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Last updated: 05/16/2006

ACTIVITIES TO DO WITH INFANTS



Birth to Six Months

- ☆ Talk and sing to the baby when you feed, diaper, and clean them.
- ☆ Imitate the sounds that the baby makes.
- ☆ Point to and say the names of the babies' mouth, ears, nose, etc.
- ☆ Place toys and other colorful objects where babies can see and/or touch them.
- ☆ Shake a rattle behind a baby's head and let the baby turn and grab the rattle.
- ☆ When you hold or rock the baby, sing lullabies or other soothing songs.
- ☆ Place babies in different positions. For example, while the baby is awake place them on their stomach so they can practice lifting their head and rolling over. Encourage hand clapping and kicking.
- ☆ Take care of baby's needs promptly. For example, feed a hungry baby or comfort a scared baby.

Six to Twelve Months



- ☆ Play peek-a-boo or other games in which you can disappear and reappear.
- ☆ Give babies a safe place where they can crawl, creep, and pull themselves up.
- ☆ Roll a ball or place a toy where babies have to reach or crawl for it.
- ☆ Give babies a toy that squeaks.
- ☆ Give babies teething toys.
- ☆ Read aloud books that have large pictures and not much writing.
- ☆ Talk to babies and name the objects as you and the baby handle them.
- ☆ Begin to teach what is allowed and what is not allowed.
- ☆ Do not force baby to interact with strangers.
- ☆ When babies indicate that they want help, provide it.
- ☆ Rock and hold babies when they are upset.
- ☆ Let babies fill containers with objects and then dump them out.
- ☆ Change toys often when babies get bored with them.

REMEMBER...

- ☆ Babies learn trust and that they are loved when you respond to their needs for food, comfort, and attention.
- ☆ Toys that go in babies' mouths should be cleaned before giving them to another child.
- ☆ Toys should be big enough so that infants cannot swallow them.
- ☆ Games and toys are the tools that infants use to learn.

Reprinted with permission from the National Network for Child Care - NNCC. Nurtall, P. (1991). Infant Development. In (*Family Day Care Facts series*). Amherst, MA: University of Massachusetts.

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Last updated: 05/16/2006





Behavioral Indicators of an Intellectual Limitation or of Learning Difficulties

1

If you are questioning whether a parent may have an intellectual disability or learning difficulties, look for some of the following possible indicators. Difficulties in these areas can *sometimes* be related to intellectual or learning problems. It is important to be cautious in drawing conclusions, since any parent could exhibit some of these difficulties or behaviors.

- Missed appointments
- Disorganization
- Poor judgment
- Sequencing difficulties
- Motor planning difficulties
- Problems with understanding time
- No follow-through on home program
- Short and long-term memory problems
- Not following through after appearing to understand a concept or discussion
- Performance fear (eg., reluctance to try a new task with his/her child for fear of failure)
- Not wanting to get down on the floor or be silly or playful with child due to worry of appearing child-like
- Attention issues
- Difficulty generalizing information
- Rigidity (eg., reluctance to do things in a different way such as moving furniture or items in the home or inflexibility regarding intervention times or school schedules)
- Parent in competition with child for toys or within play
- Child has chronic health problems such as frequent or ongoing ear infections, coughs, or rashes that may be due to lack of appropriate use of medications or medical advice



Common Personal Issues

2

The following are some issues that tend to be common for parents with intellectual disabilities. Be aware that a parent may have personal histories or sensitivities in these areas, as they can affect parenting and receptivity to learning.

- **Fragile self-esteem**
- **History of difficult learning experiences resulting in possible insecurity, resistance, defensiveness, fear of failure or inadequacy**
- **Trauma history**
- **History of rejection and loss**
- **Mental health issues**
- **History of being judged and seen as inadequate**
- **History of Child Protective Services involvement**
- **Mistrust or guardedness with professionals**
- **Poor parenting models**



Fundamental Elements of Intervention

3

BUILDING STRONG RELATIONSHIPS WITH PARENTS

Establishing strong relationships is at the "heart of the work". Building a trusting relationship between worker and parent may be slower or more difficult, but without a parent's trust, your effectiveness is doubtful.

- Give yourself plenty of time.
- The relationship you have with a parent serves as a model of attachment in the parent-infant relationship.
- Nurture the parent so that the parent can nurture his/her child.
- Use your relationship with the parent as a "lab" for the parent to learn about relationship skills including assertiveness, problem-solving, and limit-setting.
- Ask parent for feedback about you and your work; this process should be ongoing.
- Discover the parent's interests, including common interests with you, in order to build rapport.
- Consciously look for things that you like or admire about the parent when there is an abundance of worrisome behaviors or issues.

BUILDING STRONG RELATIONSHIPS BETWEEN PARENTS AND CHILDREN

A core aspect of the early intervention work is supporting the parent-child relationship. Monitoring the relationship and designing interventions that support parent-child interactions and emotional relationships are central to the work.

- Take into account the parent's disability issues when considering the parent-child activities.
- Draw in and keep parent as the central figure to the child.
- Get to know the child so that you can be more effective in encouraging positive and successful parent-child interactions.
- Be careful not to be too attractive to the child and not to "out-parent" the parent.

- Encourage activities and interactions between parent and child that incorporate the parent's interests and skills in order to increase the parent's motivation and the likelihood that these connections will continue in your absence.
- Draw parent into child's activity or find a way to involve child with parent's daily household activities (dishes, cooking, yard-work).
- Reinforce "the fun" the parent and child have together; observe, point out, and reinforce what they enjoy doing together; go for that "gleam in their eyes".
- Consider play activities that increase the physical proximity of parent and child.
- Create "linking moments" (little moments of interaction) between parent and child; for example, point out to parent something positive about his or her child such as the child showing a new skill, looking cute, or smiling at or imitating the parent.
- Work toward a goal of increasing the frequency, duration, and quality as well as the parent's initiation of the parent-child interactions.
- Videotape parent and child together when this is acceptable to the parent. This process can help parents become better observers of their children and can increase parents' understanding of the emotions and motivations behind their children's behaviors.
- View the videotape with parent, pointing out positive or enjoyable interactions, the parent's responsiveness to the child, and effective parenting strategies. Be sensitive, avoid criticism, and give the parent a chance to critique his/herself. Provide a copy for the family to watch on their own: they may gain insights from repetitive viewing.

ULTRA RESPECTFUL APPROACH

Parents with intellectual disabilities have had many experiences in which they have felt disrespected, criticized, judged as being inadequate, or scrutinized to see if they are "measuring up" to a task, including parenting. Because of these experiences, parents may be wary of service providers or defensive about being in a learning position. Therefore, it is extremely important to have an ultra respectful approach when working with parents in order to counteract past experiences and to allow for trust to build in the relationship between you and the parent.

- Be consistent, reliable, and punctual.
- Work toward the parent's goals first.
- Use collaboration with parent and avoid a stance as "the expert"
- Avoid interventions that undermine the parent's authority or status in the eyes of his or her child.

BUILDING PARENT'S OVERALL SELF-ESTEEM & PARENTING CONFIDENCE

- Demonstrate to the parent that you value him or her as a person and value his or her opinions, thoughts, and feelings; "I'm interested in what you think"; get ideas from parents and "follow their lead"; make sure to follow-through on parents' ideas.
- Look for opportunities to empower the parent and to soften or counteract the inherent power differential between you.
- Support parent's authority with his or her child and his/her role as the parent with extended family members and others in the community.
- Avoid undermining the parent's authority in the eyes of the child (e.g., by correcting the parent in the child's presence).
- Identify and reinforce parent-child activities in which the parent shines in the eyes of the child.
- Find language and strategies that do not undermine parent's confidence or self-image. (See section "The Art of Teaching and Suggesting".)
- Protect parent's self-esteem (e.g., if a parent makes a mistake, reframe or make it "ok" by saying, for example "that happens to me too").
- Look for a parent's strengths and positive qualities and build on those.
- Support the interests of the parent; increasing his or her skills will increase a parent's self-confidence.

- Find areas to view parent as knowledgeable (e.g., cooking, singing, mechanical ability or other trade skills, knowledge of his or her child); ask the parent to teach you if she knows something you do not know.
- Sensitively handle topics that you know have undermined the parent's self-confidence in the past (e.g. Special Education, CPS, "failure experiences").

EXTENDED FAMILY & CLIENT SYSTEMS APPROACH

- Support the couple relationship especially related to parenting; couple counseling may be helpful.
- With the parent's permission, establish relationships early on with significant others associated with the family; e.g., extended family, pediatrician, in-home support persons, friends, neighbors (as appropriate). These pre-established relationships can be helpful in crises or worrisome situations and can assist with coordinating services and finding solutions.
- Connect with other providers for consultation and support; share concerns and dilemmas.
- Promote respect for parent and for parent's authority with others.
- Develop and reinforce the family's natural support system.
- Support the extended family in their roles of supporting the parent; extended family is often a long-term, central support for parents with intellectual disabilities who tend to be socially isolated.
- Discover who has the power in the family and in the household and form an alliance without undermining parent's authority (e.g., with grandparent).
- Be respectful in the work with grandparents as this attitude can be critical to good outcomes.
- Mediate tensions between parents and grandparents.
- Recognize the fact that balancing support or protection with allowing autonomy of their parenting child is often an ongoing challenge for grandparents; at the same time, for parents with intellectual disabilities, needing support or assistance while maintaining autonomy and authority can be stressful and challenging.

ATTENTION TO THE CHILD'S HEALTH, DEVELOPMENT & SAFETY

- Be vigilant in monitoring and addressing safety and health issues.
- Establish with the parent early on that she/he is the "protector of his or her baby" and restate this theme in different ways throughout the work.
- Brainstorm prevention safety strategies and solutions with parents (so that they then "own" the ideas).
- Use practice and adaptive strategies to assist parents with safety and health concerns (e.g., childproofing); observe and address the giving of medications, temperature-taking, and safety during childcare activities such as bathing, feeding, and trips in the community.
- Make certain that parents know how to respond in an emergency.
- Use pediatrician as a resource in order to reinforce follow-through.
- Educate pediatrician, as needed, in adaptive communication approaches and strategies to maximize understanding and follow-through by parent.
- When parents have difficulty identifying hazards, describe potential scenarios in order to help a parent see ahead to possible dangers for his or her child.

"What do you think might happen if Johnny gets too close to the open window?"

"What would you do if Toni hurt herself badly and was bleeding?"

If you are concerned that a parent might feel patronized by this approach, this probably means that it is not an appropriate strategy for that parent.

- Sometimes there are emotional reasons for a parent's difficulty in keeping his or her child safe and healthy; e.g., a history of not having been cared for or protected him or herself as a child or current depression or other mental health issues. It may be important to address these underlying issues in order to see a change; make referrals for additional mental health services as appropriate.
- If you do not get follow-through with a safety strategy, find a way to share your concerns with the parent. Some parents will respond best to an assertive and direct approach; firm limit-setting is

particularly appropriate for safety issues. Discuss the concerns with other professionals involved with the family or with other family members when appropriate.

- When you are worried about safety, locate other supports for the family so that another individual is coming into the home; consider respite services, childcare or center-based early intervention program.
- The bottom line is the child's absolute safety; Child Protective Services may be warranted and can sometimes motivate the parent.



Adaptive Approaches and the Use of Self

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The following list includes some suggestions, strategies, and techniques for effective intervention with parents with intellectual disabilities. The suggestions may work with some families and be contraindicated with others. It is hoped that the strategies will spark interventionists' own problem-solving for working with parents with cognitive limitations. Interventions need to be tailored to what works for an individual family. Clinical judgment must be used in selecting a strategy for a family. Interventionists should always be sensitive to how their actions make the parent feel about him or herself as a person and as a parent. The goal is to support the parent's self-confidence, which affects the quality of his or her parenting and the child's overall development. Initially the worker might "pilot" a strategy and determine its effectiveness and impact on the family. When a strategy does not work or seems to bring out defensiveness in the parent, it's often effective to talk about "your" mistake or ask the parent for feedback on what would have worked better for him or her.

BEGINNING WITH A FAMILY

- Building rapport and forming a relationship is your first goal.
- Include parent and child together in your work from the beginning; it is often difficult to shift sessions to this inclusive approach when you have been focusing your attention primarily on the parent or primarily on the child.
- Hold off on addressing problem areas, if possible, until you feel that your relationship can withstand such intervention.
- Draw attention to and reinforce anything positive that you might observe, even if it is a minor glimmer in the midst of a worrisome or problem-filled situation; begin with even a minor positive before addressing problem areas.
- Incorporate the parent's goals into the initial work so parent feels that his or her desires and perspectives are important.
- Attempt to respond to an expressed or perceived need of the family. If a parent mentions a frustration, problem, or need, try to begin there; attempt to address that problem to demonstrate in a

- concrete way that you can be helpful to their family.
- Attempt to attune your body language and energy level to that of the parent's style; for example, if he or she is quiet and soft spoken, mirror the quietness.
- Make the session enjoyable.

REPETITION WITHOUT OFFENDING

- Find ways to repeat information in different words, contexts, and modalities to avoid obvious repetition. (E.g., In teaching nutrition you might talk about it, bring in different foods to try, bring in a chart, accompany parent to WIC where good nutrition is discussed, ask pediatrician to discuss child's nutritional needs, go to store together, cook with parent.)
- Often, you may need to sensitively re-visit an important parenting topic on each visit over an extended period of time.
- Seed ideas and gently return to them in different ways; allow the parent time to process information or needed change.

CONCRETE PRESENTATION OF INFORMATION

- Do with the parent; don't just "talk about".
- Link teaching to what is happening at the moment.
- Use everyday occurrences in the household (diaper changing, bathing, need for medication, meal time) as teaching opportunities to help parent become more effective with behavior management, other parenting skills, and the facilitation of their child's development.

THE ART OF TEACHING AND SUGGESTING

- Be aware that parent may be sensitive to criticism and may experience suggestions as criticism.
- Watch for signs that the parent may be feeling criticized.
- Brainstorm together with parent for solutions; give parent credit for ideas whenever possible.
- Make room for parent's ideas; take suggestions from parent and figure out how to use them.
- Make parent the knowledgeable one; e.g., "I'm wondering if Johnny might be getting ready for solid foods. Do you think so?"
- Let parent "save face":
- If a parent makes a mistake, has difficulty with a task, or doesn't know something, find ways to minimize the deficit so that the parent doesn't feel inadequate.
- Draw attention back to the task and the part that he or she is

able to do.

- Over time, a parent might be able to look at his/her deficit and still feel adequate.
- Parent might be listening even though he/she doesn't appear to be listening.
- Assess parents' tolerance of directive approaches. Some parents require assertive and direct communication. With many others, one needs to avoid being directive. With such parents, soften your position as "the expert instructing the parent". Keep parent's authority intact and phrase suggestions that allow the parent to feel free to pick and choose what works for him or her. Make sure your suggestions are compatible with the relationship you've built with the parent.
- Phrases to try when making suggestions:

"My daughter liked this..."

"My friend tried it this way."

"I saw an expert on TV who had this idea. Maybe you'd like to try it."

"Here is a suggestion you could try and see if it works for you."

"I don't know if this will work for you, but some moms have told me that they do this..."

- Use the "lightening rod" technique in which you preface suggestions with statements which might defuse defensiveness, such as:

"This might just be how I think, but..."

"I know it's hard when I talk about this."

"This might seem silly, but..."

"You might already be doing this, but..."

"You might not like hearing this, but..."

- Sandwich difficult suggestions or criticism between positive comments.
- Use humor when tolerated.

AVOIDING POWER STRUGGLES

- *Instead of immediately stating a solution or being critical respond to the parent's underlying emotional mood:*

"It sounds like this is really upsetting"

"This sounds really frustrating"

- Use empathy and understanding to avoid defensiveness.

DISCOVERING THE MOTIVATION AND HISTORY BEHIND A PARENT'S BEHAVIORS

- Attempt to elicit parent's thinking behind an action or inaction so that you may address emotional or practical obstacles.
- Gaining understanding of parent's thinking and motivations can help intervenor be less judgmental or critical of a parent.
- When appropriate, obtain information from other people involved with the family. Sometimes additional information can give you more understanding of behaviors, lack of behaviors, or resistance to a change on the part of a parent.

BEING FLEXIBLE AND ENCOURAGING FLEXIBILITY

- Being flexible and tolerating change may be difficult for parents with intellectual disabilities; persisting with the one way in which they have been successful is sometimes a strategy for parents to accommodate their disability and avoid anxiety about possible failure.
- When encouraging flexibility:
 - Select areas in which it is most critical for parents to be flexible.
 - Be reasonable in the amount of change you encourage parents to tolerate.

-When reasonable, accommodate a parent's need to do things one way only.

-Model being flexible to help parent be more flexible with his/her children.

-Positively reinforce when parent is able to be flexible.

NORMALIZE "NOT KNOWING"

- Normalizing not knowing allows for the possibility of not knowing something and still being capable.
- Worries about not knowing something increase anxiety and decrease the ability to learn and function at one's potential.
- Normalizing not knowing gives people permission to be uncertain or to need help and counteracts the tendency to hide limitations and the need for help:

"Babies don't come with instructions."

"I used to do this with Katy until a mom at the park gave me this idea."

ACKNOWLEDGE YOUR OWN FLAWS AND MISTAKES

- Showing that you are not perfect helps diffuse the power differential and communicates that it's okay to make mistakes.
- Find opportunities for the parent to point out things he or she would like you to do differently.
- Encourage parent to critique your videotaped work with the family.

DISCUSSING DEVELOPMENTAL DELAYS WITH SENSITIVITY

- For developmental specialists, when possible make progress in the child's development before discussing areas of delay. This provides a cushion for a parent to tolerate the more difficult information about a developmental delay. Also, this helps a parent feel more hopeful that the delay will improve which, in turn, increases the parent's investment in the child's development.
- Developmental delays in a child can bring up feelings and memories related to a parent's own delays or special education experiences.
- Be aware that developmental delays in a grandchild can also evoke strong feelings in a grandparent.

ATTENDING TO THE NEEDS OF PARENT AND CHILD

Attending to the needs of the parent as well as those of the child will allow you to establish a better relationship with the parent; this relationship will be an important foundation for all of your work with the family.

- Assess when you need to concentrate your focus on the needs of the parent or the needs of the child and when you can attend to both.
- Nurturing the parent can help him/her nurture the child.
- You may need to set limits on the attention you can give to the parent; for example, it might work well to have an arrangement with the parent in which you set aside the beginning and/or end of your session to focus on the parent.
- Overall, interactive work with parent and child together gets the best results.



Adaptive Strategies That Maximize Learning

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DISCOVERING THE PARENT'S LEARNING STRENGTHS AND GAPS

- If a parent has difficulty being successful with a parenting task, analyze skills needed to perform that task in order to determine where things are breaking down.
- Over time, assess a parent's learning issues (e.g., hypersensitivity to touch or difficulties with auditory or visual processing, sequencing, attention and memory.) Understanding these issues can help you better accommodate to the needs of individual parents. It might be helpful to get a consult from an occupational therapist or cognitive therapy specialist to help with assessment and strategies.
- Over time, assess a parent's level of comprehension in different ways.
- Observe a parent's parenting skills in different situations (in the home and community); find ways to observe skills rather than relying on self-report (e.g., observe a parent mixing formula rather than relying on her description of how she does this task).
- When a parent needs to perform a parenting or household task in your presence (e.g., breakfast preparation), take the opportunity to use your observation skills to assess areas of challenge or strength; this may be a more respectful and effective method of assessment than asking the parent to perform a task for you or asking him or her for self-report.
- If you never get a chance to observe a parenting skill that you wonder about, you might want to suggest in a very respectful way that you do it together. (E.g., "It's such a hot day, Sally might really like to take a bath. Would you like to do that?")
- Be careful not to put the parent "on the spot" or make him/her feel he/she is being tested.
- Be careful not to make assumptions about what a parent can and cannot do; he or she may have unexpected skills or challenge areas.

TAILORING INTERVENTION

Tailor your method of teaching as well as the environment to accommodate the way an individual parent learns or best functions.

- Pace how much information you give parent in each session; observe how much the parent can take in.
- Have patience with the level and speed of progress; be aware that progress may be slower.
- Grade the level of difficulty of a task for the parent; when a parent needs assistance, provide as much help as needed so parent can successfully complete a task; gradually decrease assistance until he/she has mastered the needed skill.
- When assisting with a task, verbalize your own thinking process and observations to facilitate similar problem-solving in the parent. (E.g., "I don't know how it is for you, but it's easier for me to do this part first so that I don't forget it later"; "It looks to me that Joey likes to sit here when he colors. What do you think?")
- Create activities that use the parent's strengths whenever possible.
- Experiment and find adaptive strategies that minimize the parent's learning difficulties:

-For parents with processing problems, you might try: decreasing background noise; placing yourself where parent can see your face when you are talking; limiting the length of sentences; increasing pauses between sentences; avoiding too many questions in a sequence.

-For parents who have memory problems, you might try: using a feeding or medication chart or an alarm watch to remind a parent about feedings or medication; providing a calendar and helping parents learn to use it for keeping track of appointments; writing down information for parents to remember and helping them to begin writing down things to remember for themselves; using photos or pictures for prompting.

-If parents have difficulty with reading, telling time, measuring, or math, you might try: using an easy-read or talking thermometer; using pre-mixed formula; making marks on a medicine dropper; using photos or pictures rather than using the written word; using TV programs as a "clock" to help remind a parent about feedings or snacks.



Taking Care of Yourself and Recognizing the "Good Stuff"

6

- Don't worry alone; reach out to co-workers or others who are supporting the family.
- Get supervision for support.
- Get mental health supervision/consultation for yourself if needed.
- Look for more quality interactions and even small "linking moments" between parent and child.
- Recognize small changes happening in the parent; learn to recognize and comment on such things as:
 - Parent demonstrating confidence
 - Parent sharing something that is difficult for him or her
 - Parent demonstrating a strength
 - Parent telling you something new the child did
 - Parent asking questions or showing assertiveness
- Use videotape to document progress over time.
- Remember that even modest changes in the quality of the parent-child relationship can have a significant impact for that child in the long-run.
- Take pleasure in little successes.